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ABSTRACT

This annotated bibliography provides information on Alzheimer's disease and other forms of dementia in older adults. Written for both educators and consumers, citations especially appropriate for family caregivers, friends, neighbors, and other family members are identified with an asterisk (*). A brief introduction discusses the incidence of Alzheimer's disease in this country and recognizes the needs of caregivers. Citations in the bibliography are organized under the categories of: (1) books; (2) brochures; (3) journals on Alzheimer's disease; (4) special editions on dementia; and (5) videos. Also included are lists of sources of additional information and organizations concerned with issues of aging, as well as the name and address of the reviewer who helped in the selection of materials to be included in the bibliography. (NB)

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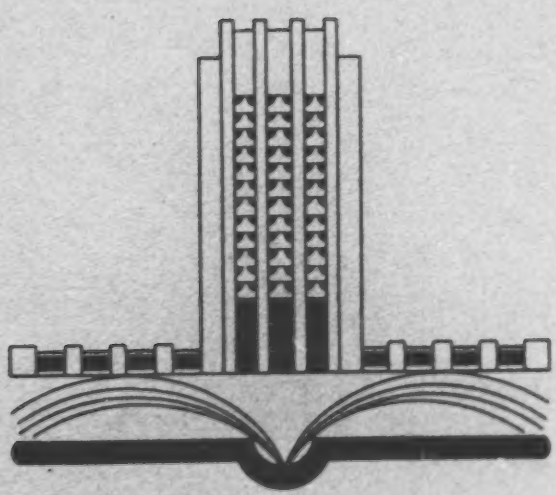

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SELECTED RESOURCES ON DEMENTIA AND ALZHEIMER'S DISEASE IN THE ELDERLY: AN ANNOTATED BIBLIOGRAPHY FOR EDUCATORS AND CONSUMERS

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The authors express their appreciation to Sandra L. Facinoli, Technical Information Specialist, and the Information Centers Branch support staff at the National Agricultural Library for expediting the development and distribution of this series on aging.

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In recent years, she has pursued a strong interest in gerontology. She also has served as the chairperson of the first national Extension Committee on Policy-sponsored workshop on aging in Dallas in 1976.

This bibliography represents the research conducted by Dr. Frazier during her 6-month sabbatical with the National Agricultural Library, U.S. Department of Agriculture. It is one of 3 publications that provides comprehensive coverage on several topics in gerontology.

GLENN I. KIRKLAND, a retired Johns Hopkins physicist, is a national authority on Alzheimer's Disease and one of the country's leading advocates for caregivers of Alzheimer's Disease victims.

Mr. Kirkland has been a participant in two award winning television programs developed at the University of Maryland Medical School in Baltimore, "Living with Grace," and "Caregiving With Grace." He is the author of several publications related to dementia and Alzheimer's Disease.

Mr. Kirkland recently received a prestigious Senior Citizens "Hall of Fame" certificate of recognition and a Maryland Extension Specialists' Association Award for meritorious service.

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Ms. Hayes recently completed a one-year assignment with the Joint Council on Food and Agricultural Sciences. As the Leader of the Reports Staff, she was responsible for the development and distribution of three congressionally mandated reports related to agricultural research, extension, and higher education. Upon her return to the Library, she was appointed coordinator for the Technology Transfer Information Center.

INTRODUCTION

Alzheimer's Disease is one of the most common causes of dementia in the elderly. It has been labeled the disease of the century, and the "silent epidemic." It is becoming a problem of major proportion for the United States. National organizations and state councils have been established to coordinate and monitor state and community efforts on the disease.

It is currently estimated that more than 4 million people over the age of 65 suffer in various degrees from debilitating mental diseases or dementia. Although the probability of having Alzheimer's at the age of 65 is about one in twenty, the probability appears to be approximately one in three or four at the age of 85.

The social impact of dementia is heightened by the fact that the segment of our population above the age of 80 is growing more rapidly than any other corresponding age bracket.

It is evident that caregivers of Alzheimer's victims are the mainstay of the Nation's efforts to cope with this disease. A major portion of the literature is directed toward the caregivers. In fact, they have provided quite a bit of information on day-to-day experiences with victims in the family situation.

Caregivers need information on a variety of subjects. Information ranges from general background material on legal and financial matters to detailed techniques for dealing with specific behavioral problems of the patient. Primary caregivers need all the assistance they can obtain and deserve accolades for the significant role they play in patient support.

Selected Resources on Dementia and ALzheimer's Disease in the Elderly is divided into the following categories: Books, Brochures, Journals, Special Editions, Videos, Organizations, and Additional Information. Citations marked with an asterisk (*) are especially appropriate for consumers including family caregivers, friends, neighbors, and other family members.

BOOKS

Adult Day Care For Persons with Alzheimer's Disease and Related Disorders: A Training Manual for Staff, Gloria Levine and Joan Scharf. Cleveland, OH: Menorah Park Center for the Aging, 1987.

Background information and useful suggestions for those involved with care of the demented in an adult day care center are provided. This book parallels a 22 minute video presentation on the same subject.

A Better Life: Helping Family Members, Volunteers and Staff Improve the Quality of Life of Nursing Home Residents Suffering from Alzheimer's Disease and Related Disorders, Dorothy H. Coons, Lena Metzelar, Anne Robinson, and Beth Spencer. Columbus, OH: The Source for Nursing Home Literature, 1986.

This book resulted from a national study of caregiving families. Among other things, it describes three examples of an exciting approach to caring for people with dementia in a nursing home setting.

* Also My Journey: A Personal Story of Alzheimer's, Marguerite Henry Atkins. Wilton, CT: Morehouse-Barlow, 1985.

This is an emotion-filled account of how one woman dealt with her husband's mental and physical deterioration from Alzheimer's disease.

* Alzheimer's Disease: A Guide for Families. Lenore S. Powell and Katie Courtice. Reading, MA: Addison-Wesley Publishing Company, 1983.

The authors discuss with the gamut of emotional pressures on caregivers and illustrate points from real life situations.

* Alzheimer's Disease: The Silent Epidemic, Julia Frank. Minneapolis, MN: Lehner Publications Company, 1985.

This is an easy to read publication and would be most appropriate for young adults and teenagers.

* Care of Alzheimer's Patients: A Manual for Nursing Home Staff, Lisa P. Gwyther. Washington, D.C.: American Health Care Association/Chicago, Il: Alzheimer's Association, 1985.

A brief review of some important considerations about Alzheimer's patients is provided. Methods of dealing with specific behavioral problems are suggested. Copies may be obtained from either group.

* Caring: A Family Guide to Managing The Alzheimer's Patient At Home, Fredericka Tanner and Sharon Shaw. New York, New York: New York City, Alzheimer's Resource Center, July 1985.

A comprehensive 100 page, illustrated manual that includes detailed step by step guidelines for managing the Alzheimer's patient at home through the various stages of the progressive disease. To obtain a copy, write to: Fund for Aging Services, New York City Resource Center, 280 Broadway, Room 214, New York, New York, 10007.

* Daughters of the Elderly: Building Partnerships in Caregiving, Jane Norris, (ed.). Bloomington, IN: Indiana University Press, 1988.

Almost 5 million of the 30 million persons over 65 are cared for chiefly by women family members. This book offers supportive information and experiences. Comments and advice are provided from professionals to assist caregivers sort out the physical, mental, and emotional aspects of aging and caregiving.

Design for Dementia: Planning Environments for the Elderly and the Confused, Margaret P. Calkins. Owings Mills, MD: National Health Publishing, 1988.

Many simple techniques for providing an appropriate environment for persons with dementia are given in this book.

* Getting Through: Communicating When Someone You Care For Has Alzheimer's Disease, Elizabeth Ostuni and Mary Jo Santo Pietro. Princeton Junction, NY: The Speech Bin, 1986.

Four major components of communication discussed in this book are the: (1) person with dementia, (2) caregiver, (3) communication between patient and caregiver, and (4) communication environment.

* Grandpa Doesn't Know It's Me, Donna Guthrie. New York, NY: Human Sciences Press, Inc., 1986.

This book deals with potential concerns of the young child who has a close relative with Alzheimer's Disease. It answers such questions as: What is wrong? Did I do anything to cause it? Will I get it? Why did it happen? To help children better understand the difficult situation with their relative, this book can open dialogue between parent and child.

Handbook of Geriatric Assessment, Joseph J. Gallo, William Reichel, and Lillian Andersen. Rockville, MD: Aspen Publishers, Inc., 1988.

The authors provide a set of assessment tools for the evaluation of mental, functional, social, economic, physical, maintenance, and geriatric status of individuals.

* How to Care for Your Parents: A Handbook for Adult Children, Nora Jean Levin. Washington, DC: Storm King Press, 1986.

This paperback lists and discusses twenty eight specific things a person needs to consider when caring for a functionally-disabled elder.

Losing A Million Minds: Confronting the Tragedy of Alzheimer's Disease and Other Dementias, Office of Technology Assessment. (OTA-BA-323). Washington, D.C.: Government Printing Office, 1987.

Prepared at the request of several committees of Congress, this report discusses the medical, social, political, and financial aspects of dementia in the elderly and assesses the impact of these diseases on the Nation.

* Managing Grief and Bereavement: A Guide for Families of Memory-Impaired Adults and Other Chronically Ill Persons, Edna L. Ballard. Durham, NC: Duke University Medical Center, 1989.

Anticipatory grief and realized grief are discussed in this book. It includes ways of dealing with bereavement and is written to support family caregivers.

The Myth of Senility: The Truth About the Brain and Aging, Robin Marantz Henig. Washington, D.C.: American Association of Retired Persons, Revised 1985.

The author explains what is and is not known about memory, brain changes with age, intelligence, Alzheimer's disease, senility, and the environment as it affects the brain.

Psychiatric Treatment of Alzheimer's Disease, Group for the Advancement of Psychiatry. New York, NY: Brunner/Mazel Publishers, 1988.

Diagnosis and treatment of dementia is covered. A set of case examples and several rating scales are included.

Social Work and Alzheimer's Disease: Practical Issues with Victims and Their Families, Rose Dobrof (ed.). New York, NY: The Haworth Press, 1986.

A series of papers on a variety of topics related to Alzheimer's Disease is presented in this document.

* The 36 Hour Day: A Family Guide for Persons with Alzheimer's Disease, Related Dementing Illnesses and Memory Loss in Later Life, Nancy L. Mace and Peter V. Rabins. Baltimore, MD: The Johns Hopkins University Press, 1981.

This remains one of the most comprehensive publications available on the topic. It is authoritative, relevant and has been translated into Spanish and seven other languages.

Treatment Development Strategies for Alzheimer's Disease, Thomas Crook, Raymond Bartus, Steven Ferris, and Samuel Gershon. Madison, WI: Mark Powley Associates, Inc., 1986.

This report provides information on the status of research in a number of areas and a review of on-going federal research programs.

Treatments for the Alzheimer's Patient, Lissy F. Jarvik and Carol Hunter Winograd. New York, NY: Springer Publishing Company, 1988.

Clinical care, family and community interventions, policy, and research are topics of the four main sections of this book. Individual chapters are prepared by specialists in their field.

* Understanding Difficult Behaviors: Some Practical Suggestions for Coping with Alzheimer's Disease and Related Illnesses, Anne Robinson, Beth Spencer, and Laurie White. Ypsilanti, MI: Eastern Michigan University, Geriatric Education Center of Michigan, 1989.

The main focus is on how the caregiver can cope with specific behavioral challenges brought on by caregiving responsibilities. This is an 80 page document with easy to read print.

BROCHURES

* Coping and Caring: Living with Alzheimer's, Charles Leroux. Washington, D.C.: American Association of Retired Persons, 1986.

Produced as part of AARP's Health U.S. Campaign, and in cooperation with Alzheimer's Organization (ADRDA, Inc.), this brochure provides consumers with information about important health care issues and also specific answers about Alzheimer's disease.

* Dementia and Alzheimer's Disease in the Elderly. Billie H. Frazier and Glenn I. Kirkland. College Park, MD: The University of Maryland Cooperative Extension Service Bulletin 335, 1988-1989.

The authors include sections on: dementia; Alzheimer's disease; caregiving at home; legal and financial issues; community resources; and nursing home care.

* Long Term Care: A Dollar and Sense Guide, Susan Polniaszek and David Lewis. United Seniors Health Cooperative, 1334 G Street, N.W., Suite #500 Washington, D.C. 20005, 1988.

Major questions raised about long term care are answered in this guide as well as information regarding long term care services and alternative means of payment.

* Selected Books on Alzheimer's Disease and Related Topics: An Annotated Bibliography, Glenn I. Kirkland. Baltimore, MD: Alzheimer's Association, 1989.

This is a packet of brief, informal reviews of selected publications of interest to consumers. Each review was prepared for publication in the newsletter of the local Alzheimer's Association chapter.

JOURNALS ON ALZHEIMER'S DISEASE

Alzheimer's Disease and Associated Disorders-An International Journal. Western Geriatric Research Institute, P.O. Box 368, Lawrence, Kansas 66044.

Published quarterly, this journal is an international medium for publication of authoritative and original scientific contributions with primary emphasis on research related to dementia.

American Journal of Alzheimer's Care and Related Disorders and Research. Prime National Publishing Corporation, 470 Boston Post Road, Weston, Massachusetts 02193.

Articles of general interest and research abstracts are included in this bi-monthly journal.

SPECIAL EDITIONS ON DEMENTIA

Alzheimer's Disease and Associated Disorders-An International Journal, 1(1), 1987.

This special edition contains Dr. Alois Alzheimer's original case report which he presented at the meeting of Southwest German Psychiatrists on November 3, 1906.

Generations, VII(1), Fall 1982. The Journal of the Western Gerontological Society, Western Gerontological Society, 833 Market Street, Room 516, San Francisco, CA 94103.

This edition is devoted to Alzheimer's Disease and Related Disorders and includes topics on: diagnosis; legal views; research; genetics; care; depression; community perspectives; self-help groups; and other pertinent issues.

Generations, IX(2), Winter 1984. The Journal of the Western Gerontological Society, Western Gerontology Society, 833 Market Street, Room 516, San Francisco, CA 94103.

An Update on Alzheimer's is the theme of this publication. Topics range from diagnosis to research to aluminum to poetry. Day care, sleep and medical imaging are also covered.

Journal of Gerontological Nursing, Slack Inc., Thorofare, NJ 08086 "Alzheimer's Disease: An In-Depth Report 1982-1983". Pride Institute Journal of Long Term Home Health Care, 3(4), Fall 1984.

Focusing on "Alzheimer's Disease at Home: Helping the Victims and the Caregivers", this publications includes special reports and book reviews prepared by well known authorities.

Journal of Gerontological Social Work, The Haworth Press, Inc., New York, NY, "Social Work and Alzheimer's Disease - Practical Issues With Victims and Their Families", 9(2), Winter 1985/86.

Contents include discussions on special nursing home units, social work groups, working with families, educational/support groups, adult day care, and family respite. Book reviews are provided.

"Long-Term Care: A Dollar and Sense Guide," Susan Polniaszek and David Lewis. United Seniors Health Cooperative, 1334 G Street, N.W., Suite #500 Washington, D.C. 20005, 1988.

Major questions raised about long term care are answered in this guide as well as information regarding long term care services and alternative means of payment.

Pride Institute Journal of Long Term Home Health Care, 3(4), Fall 1984.

Focusing on "Alzheimer's Disease at Home: Helping the Victims and the Caregivers," this publication includes special reports and book reviews prepared by well known authorities.

Provider, 12(5), May 1986. American Health Care Association. Washington, DC, 1200 15th St. N.W. 20005.

Nationally known authors make significant contributions in this edition that covers some of the best current thinking and actions. The materials are written for health care providers.

VIDEOS

The following ten videos are available from:

Video Services, Department of Physical Therapy
University of Maryland School of Medicine
32 South Greene Street
Baltimore, MD 21201
(301) 328-5497 or (301) 328-7720

1. Living with Grace, an award winning video presents a series of vignettes taken during five months in the life of Grace, who is afflicted with Alzheimer's Disease. Focus is on the husband's efforts so their life can continue with dignity and meaning. It was videotaped six years after the initial diagnosis (30 minutes).

2. Caregiving with Grace was videotaped ten years after the initial diagnosis. It documents daily care provided by Grace's husband and a foster home caregiver. Both discuss practical and emotional solutions for caregiving with Grace (35 minutes).

   These two programs illustrate changes that occur in an Alzheimer's victim over a ten year period.

3. Perspectives on Grace: Medical Implications is designed to be used in conjunction with Living with Grace and Caregiving with Grace. A noted physician comments on medical and social implications of her condition and their impact on the family (20 minutes).

4. Perspectives on Grace: Nursing Care Implications presents an overview of behavioral and emotional symptoms associated with various stages of Alzheimer's disease and dementing illnesses. Commentary is based on the case presentation in the documentaries, Living with Grace and Caregiving with Grace. Specific caregiving strategies are addressed (20 minutes).

5. Nursing Care for Elderly Dementia Patients is a presentation on the cognitive and behavioral manifestations of dementia syndromes. The emphasis is on the use of the nursing process to develop, implement, and evaluate a comprehensive patient care plan (25 minutes).

6. Caregiver Stress includes strategies for stress management, stress reduction, coping with caregiving roles, and improving the general and the mental health of the caregiver. The video is directed toward home caregivers (25 minutes).

7. Depression and Dementia presents a discussion on depression in elderly dementia patients who are residents in long-term care facilities. The physician defines depression, explains how to identify it, and suggests intervention, management, and treatment (20 minutes).

8. What is Dementia? provides discussion on Alzheimer's disease and related dementing illnesses. A physician provides the basic overview of symptoms and describes how a diagnosis is made. This tape serves as an introduction to Alzheimer's disease for health professionals, volunteers and family caregivers (16 minutes).

9. Solutions for Today examines medical and psychosocial interventions and addresses what can be done for dementia patients and their families. A physician provides an overview of practical principles for responsive caregiving, and exploring challenges and rewards (20 minutes).

10. Medication and Dementia describes the use, precautions, and side effects of medications used with patients having Alzheimer's disease and related dementing illnesses (20 minutes).

* * * * * * * * *

The following video is available from:

Oregon Health Sciences University School of Nursing
3181 S.W. Sam Jackson Park Road
Portland, OR 97201
(503) 279-7709

Working With the Confused Elderly presents specific verbal and nonverbal caregiving techniques designed to enhance coping skills such as dealing with problems of wandering, disorientation, and paranoia (29 minutes).

* * * * * * * * *

The following videos are available from:

Alzheimer's Disease Project
The University of Michigan
300 N. Ingalls Building, Room 952 N.E.
Ann Arbor MI 48109-2007
(313) 764-8298

Terra Nova Films, Inc.
9848 South Winchester Avenue
Chicago, IL 60643
(312) 881-8491

1. Wesley Hall: A Special Life documents a cooperative project between the Institute of Gerontology of the University of Michigan and a nursing home to improve the quality of life of Alzheimer's disease victims (28 minutes).

2. Helping People With Dementia and Activities of Daily Living demonstrates the use of task breakdown for working with Alzheimer's patients. Examples of activities included are: brushing the teeth; setting the table; and getting dressed (Slides on video; 22 minutes).

3. Designing the Physical Environment For Persons With Dementia presents environmental modifications that can be made to deal with disorientation, spatial problems, and general sensory loss. It was developed in conjunction with the Wesley Hall Pilot Project (Slides on Video; 20 minutes).

* * * * * * * * *

For information on a lending library of 400 training videos and over 300 pieces of printed material related to dementia and Alzheimer's Disease, contact:

The Hillhaven Foundation
Dept. TJ
1148 Broadway Plaza
Caller Service 2264
Takoma, WA 98401-2264
(206) 756-4831

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SOURCES OF ADDITIONAL INFORMATION

Typical resources for most geographical areas include the following:

* Toll Free HOTLINE 1-800-621-0379
* Center on aging at a university
* County Cooperative Extension Service (under county government in telephone book)
* Dementia clinics
* Local, county, area, or state office on aging
* Local Alzheimer's Association chapter

ORGANIZATIONS

Specific agencies, organizations and groups that provide information related to many topics on aging include:

Alzheimer's Association (A.D.R.D.A., Inc.)
70 E. Lake Street
Chicago, IL 60601-5997
1-800-621-0379

Alzheimer's Society of Canada
1320 Yong Street
STE 302
Toronto, ONT
M4T 1X2
416-925-3552

American Association of Retired Persons
1909 K. Street, NW
Washington, D.C. 20049
(202) 872-4700

American Parkinson's Disease
Information and Referral Association
The Johns Hopkins Hospital, 1-130 Meyer
600 North Wolfe Street
Baltimore, MD 212205
(301) 955-8795

Family Survival Project
425 Bush Street
Suite 500
San Francisco, CA 94109
(415) 434-3388

The French Foundation for Alzheimer Research
11620 Wilshire Boulevard
Los Angeles, CA 90025
(213) 470-5462

Huntington Disease Society of America
140 West 22nd Street
New York, NY 20011-2420
(212) 242-1968

National Council on Aging, Inc.
600 Maryland Avenue, SW
Washington, D.C. 20020
(202) 479-1200

National Institutes of Health
Public Health Service
U.S. Department of Health and Human Services
9000 Rockville Pike, Building 31
Bethesda, MD 20205
(301) 496-1752

National Library of Medicine
8600 Rockville Pike
Bethesda, MD 20894
(301) 496-6095

REVIEWER

The information that appears in this bibliography was peer reviewed and selected according to the following criteria: accuracy, objectivity, and accessibility of information; credibility of the source; balance of viewpoint; clarity; variety; and readability.

The following university professional reviewed the literature:

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